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SUPPORTING FAMILIES: INTERDISCIPLINARY PRINCIPLES OF INTERVENTION

Grief and loss are by far some of the most devastating experiences that we face. When that loss is the death of a child, it is especially devastating. Most important, the grief associated with the loss of a child is not a singular event, but instead is an ongoing process. It is chronic. As one parent has said to us, “the grief of losing my baby is like a meteorite landing on the Earth and you are constantly trying to figure out how to ever live around the destruction.”

Grief is the internalized part of loss and is marked by how we feel. The pain is so intense and so heartbreaking for parents because they have lost their profound and loving connection with their child. However, the way in which pain and grief manifests is as different as is each one of us. Still, our society places enormous pressure to “get over the loss.” Even our workplaces preemptively decide how many days we should take off for specific losses—be it a parent, a brother, a sister, a grandmother, a spouse, and rarely a child. Usually, your best friend of 30 years “doesn’t count” nor might a beloved uncle who may have raised you. Obviously, our sense of loss and grief depends on what the person is to each of *us* and how we feel about the death, not some formula of how we are told we should grieve.

Dr. Elizabeth Kubler Ross is universally known for her model regarding grief and loss. She thought about grief in terms of stages we experience after a death of a loved one. The stages include shock and numbing, denial and yearning, anger, depression, and resolution. Recently David Kessler has added a sixth stage of grief: finding meaning. Unfortunately, the idea of stages gives the impression that grieving is a linear and smooth progression. Kubler-Ross may have inadvertently used a confusing term when she used the word “stages” because she never considered these “stages” as building on one another even though her model is often interpreted in that way. As a result, it is often the case that some parents feel they should follow a timetable or schedule for their grief and get concerned when their emotions are not “on schedule.”

Another way to think about grief is through the work of William Worden who theorizes about the “tasks of grief.” These tasks include:

- Accepting the reality of grief

This is when parents struggle to face the death of their child. This task is often aided through tasks like spending time with the body, arranging for a funeral or memorial service, sitting shivah, or taking care of the grave site. Sadly, these rituals and their associated significance are often overlooked or downplayed when there is a miscarriage or stillbirth.

- Processing pain and grief

As mentioned, the grief process is unique to every person. Some people are numb for a long while, some cry or prevent themselves from crying, some feel like they are “going crazy,” some have a short fuse, some sleep all day, some don’t sleep at all, etc. What can help in circumstances such as these is for the grieving parent to find purposeful actions, which can become an outlet for their pain. This could include planting and caring for a tree or bush, participating in a parent grief group, working toward passing relevant legislation, or developing a fund or foundation. The purpose here is *not* to avoid the pain and sorrow but find a way to manage it.

- Adjusting to the world without your loved one

This does *not* mean that parents should “forget about the child” or “move on” but instead that they continue the connection to the child and move forward. This might include writing stories or books about the baby, journaling, or painting words of hope on stones and putting them around the grave site. Still, it will be a long, long, long time until a parent can function again and remember their deceased child with a smile instead of only their tears.

In talking about the task of making meaning of loss of a cherished loved one, Worden says, “People always want to know if there is life after death for their loved ones. I believe there is, but more importantly, there is life after death for the living. I want to help them find meaning that honors their loved ones. Sometimes when we are at our worst, we can find our best.”

Principles of Intervention

The cautious good news is that when we encounter, work with, or have a personal connection to a parent/family, there are eleven principles that should guide our response:

Take Care of Yourself

It is natural to be overwhelmed when we encounter the death of a child. This can make it difficult to handle the needs of grieving parents or even to be sensitive to their pain. It is even

more difficult if we don't take care of ourselves. In short, we can't take care of others if we don't take care of ourselves. Having regular interactions with family, friends and peers is one way to support each other and to share ideas and thoughts about supporting parents.

Understand your own Feelings and Experiences about Grief and Loss

Connected to the need to take care of ourselves is that when we work with families who have had the horrific experience of losing a child, it is not unusual to feel anxious about our own mortality and the mortality of those we love. We all understand events in countless ways based on our own experiences in the world and thus it can become challenging to listen actively and sensitively, when our own beliefs and values based on those experiences interfere. This may impair our ability to help others. One way to prevent this is to think about our own feelings and reactions including why death is most frightening to us, what we feel guilty about related to loss and how we ourselves deal with grief and loss. We also need to dig deep within ourselves and consider why it may be so hard for us to hear what parents say about death.

Educate yourself about Grief and Loss

It is the case that if we have knowledge and information about the impact of the death of a child on a family, we will be positioned better to provide support. Once we get in touch with our own feelings, beliefs, values and experiences it becomes easier to understand our own responses and enable us to feel more comfortable around grieving parents and to reassure them and validate their experiences.

Demonstrate Cultural Sensitivity

Probably there is nothing more distinctive about death and loss than the unique manner in which the way individuals, families and the culture deal with it. Of course, the experience of death and loss is universal, but the behavior, traditions, rituals, and practices around it are informed by one's cultural norms, beliefs, and expectations.

We also need to remember that there are as many differences within a culture as outside a culture. Even if families look like us, act like us, or talk like us they don't necessarily think or feel like us and we should *never* assume that they do. One way to get beyond the bias is to *always* ask families about their personal views, religious and spiritual beliefs, and their traditions, practices, and rituals.

Recognize that Everyone Grieves in Different Ways

As noted, grief is as individual as each of us and manifests uniquely. It is related to our relationship to the person whom we have lost. In most families, the only thing that each member of the family has in common is that they all experienced the loss of the same person. There will be as many reactions as there are people involved. Simply because others respond

differently to the loss than we do does not mean that they are not in emotional pain. For example, it is not at all unusual for family members to think that others are not grieving in the “correct” way. One provider told us that their client, a deceased child’s mother, wasn’t “grieving at all,” but what she was really saying is that her client wasn’t grieving in the way that she thought she should.

Don’t Underestimate the Power of Relationships

Research suggests that having a positive relationship with another person and a strong support system is the most powerful tool available to help us heal. Families appreciate the friends and family who grieve with them, comfort them, and support them for both the short and long-term.

One way to establish rapport is to demonstrate patience, empathy, positive regard and respect (Rogers). For example, when we always refer to the child by name, we honor and respect his or her importance. When we talk directly and sympathetically about the loss of the baby and actively listen to parents’ pain, we help them to feel accepted and understood.

Quite the opposite can happen too. Many parents who have had a miscarriage have shared with us that they have been told to not worry because they can “always have another baby,” as if “another” baby could ever substitute for the baby they lost and loved.

Stabilize the family

Judith Herman reminds us that “trauma robs the victim of a sense of power and control and that the first task of recovery is to establish the survivor’s safety.” Of course, Herman was talking about bodily, physical, emotional, and spiritual safety. One of the first things we can do to help families is to assist them to focus on bodily control—sleeping, eating, exercise and basic health needs.

We also need to reach families where they are. For example, some families want to focus on reading websites and other written resources, some want to talk about the loss while others do not, some may want support for their surviving children. It is imperative that we give them what they need at the time, not what *we* think they need.

All families who are grieving need us to “bear witness.” (Herman) Talking about the loss helps people heal but *they* must lead the way and it is equally important to respect their right not to talk. We need to be prepared that some families will decline offers to see or speak to us. We can check back with them occasionally if for no other reason than to let them know somebody cares.

Give Parents Permission to Tell their Story

When a baby dies, a family faces an additional avalanche of losses including the family and future of which they dreamt, a piece of themselves, and their hopes for the future.

Many parents benefit from telling their story repeatedly and from having someone listen with empathy, responsiveness, and acceptance. Even if we know some of the details or have talked with them previously, we can continue to have a dialogue about their baby e.g. how they picked the baby's name, what they were like, what they loved most about him or her, their favorite memory about the baby, etc. We often hear from people who want to help but don't talk about the deceased child with a parent because that they are afraid that they will "make the parent cry." In fact, we don't make them cry but we *let* them cry.

It is equally important to recognize that these same parents also need distractions so that they are not experiencing pain constantly. Parents often wish for others to share information about their own lives, and not to be treated as if they are too fragile for social connectedness.

Give the Family Information and Support about the Loss

It is not uncommon for parents to feel like they are "going crazy." What we can do to help is prepare families for these strong and startling emotions and let them know that they will likely experience waves of grief that seem to come out of nowhere. Providing psychoeducation such as this can reduce feelings of isolation and give permission to express emotions.

It is often helpful for parents to talk about how to cope with such a tragedy. Many are in such acute and devastating pain that they believe they will never be able to function ever again. Since most people have had other difficult things happen to them in the past (although none as horrific as losing a child), they can be reminded that in those circumstances they did cope and that at least, in part, they can translate that coping to this catastrophe.

Provide Resources when and if the Family Requests them

As noted, parents understandably need reassurance that their thoughts and feelings are valid and that they are not losing their minds. When and if appropriate, we can offer or recommend books, articles, or pamphlets that discuss causes, feelings and experiences around pregnancy loss or infant and child death. Such resources typically provide parents with reassurance and information about their grief.

Support groups may also serve as a source of comfort. When the tragedy is shared with others who have had a similar tragedy, it diminishes the sense of isolation that parents experience. As they see others cope, it may remind them that the agony that they are experiencing will not last forever and offers hope that they will be able to function again.

Don't do this alone

It takes all of us—a village-- to help a family deal with such a horrific calamity. We need to reach out to others and work together to keep from becoming traumatized ourselves, and to ensure that our families have access to comprehensive, tailored support. To make a referral to our Center, simply **contact us**.